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Abstract

While Type 1 diabetes (T1D) is generally associated with childhood, half of all cases occur in adulthood. The adaptive strategies individuals employ during the initial adaptive phase may have an important impact on their risk of future diabetes complications and their psychosocial well-being. We conducted a systematic review of six databases and included nine qualitative studies in a meta-synthesis the aims of which were: to develop a better understanding of how adults newly diagnosed with T1D experience the diagnosis and the phenomena associated with the early process of adaptation to life with diabetes. The meta-synthesis identified five constructs that shaped and influenced the early adaptive process: disruption; constructing a personal view of diabetes; reconstructing a view of self; learning to live with diabetes; and behavioural adaptations. The adaptive processes of adults to a diabetes diagnosis are highly referenced to prior life experiences, social habitus and psychological orientation.

Introduction

Type 1 diabetes (T1D) is generally associated with childhood or early adolescence, where the peak incidence occurs (Tuomilehto, 2013), however, more than half of the diagnoses occur in adulthood with no upper age limit (Thunander et al., 2008). To date, while there have been many studies of the impact a diabetes diagnosis has in children, young people (Delamater, de Wit, McDarby, Malik, & Acerini, 2014), and their families (Whittemore, Jaser, Chao, Jang, & Grey, 2012), there has been less interest in the immediate impact a new diagnosis of T1D may have in adult life. The adaptive trajectory of a diagnosis in adulthood may be distinct from that of children and adolescents, as adults' life experiences and perspectives are more developed (Lašaitė, Ostrauskas, Žalinkevičius, Jurgevičienė, & Radzevičienė, 2016).

In the context of chronic illness, adaptation is described as the process of responding to the disruption and stressful events imposed by the disease and its impact on identity leading to emotional and behavioural outcomes (de Ridder, Geenen, Kuijer, & van Middendorp, 2008; Moss-Morris, 2013; Sharpe & Curran, 2006). These processes and outcomes have been identified as contextual to the nature and extent of the disease and the characteristics and circumstances of the individual (de Ridder et al., 2008; Moss-Morris, 2013; Stanton, Revenson, & Tennen, 2007). Adaptation in chronic disease has been characterised as a dynamic process with outcomes evolving over time across multiple life domains following the disease trajectory (Moss-Morris, 2013; Pollock, 1986). The process of adaptation is manifest in the cognitive, emotional and behavioural strategies used by the individual as they accommodate the effects of the disease (Moss-Morris, 2013; Sharpe & Curran, 2006). Cognitively, people with chronic conditions must reconcile their disease within their daily lives and in relation to their self-identity in the context of their past, present and future lives. They also need to seek information to gain the knowledge to adjust their present lifestyle and acquire the skills to make the behavioural changes needed to deal with their new life situation while enabling them to

continue their day-to-day life (de Ridder et al., 2008; Moss-Morris, 2013; Stanton et al., 2007). Hence, adaptation is a multifaceted process involving re-establishing self-identity, (Moss-Morris, 2013; Sharpe & Curran, 2006; Stanton et al., 2007; Whittemore & Roy, 2002) adjusting familiar skills or behaviours *and* developing new routines and automated actions or behaviours to limit the impact the disease may have on well-being and quality of life (Cohen & Lazarus, 1979). In the context of a life with T1D this demands developing a range of new behaviours such as performing insulin injections and blood glucose measurements and making adjustments in relation to established behaviours such as eating and taking exercise (Mol, 2009). These complex and time consuming new behaviours and routines must be developed rapidly during a period of physical and emotional turmoil. In adulthood, the diagnosis also demands significant personal and social adaptations which may have an impact on prior life plans, relationships and economic well-being (Hernandez, 1996; Whittemore & Roy, 2002). This formative period of adaptation to diabetes may be important in shaping an individual's future orientation to diabetes, their level of engagement with the disease and ultimately to their long-term psychological well-being and risk of diabetes complications.

While there have been significant technical advances in diabetes treatment in recent years, it appears that these have failed to improve both clinical and psychological outcomes for people with diabetes. Currently, less than half of adults living with T1D achieve the recommended treatment targets for blood glucose necessary to prevent these complications (McKnight et al., 2015), suggesting that accommodating the behaviours necessary for achieving these targets in daily life is challenging (Snow, Sandall, & Humphrey, 2014). The complexity of living with diabetes is further illustrated in studies of adults with longer standing T1D showing significant psychological burden with high levels of diabetes distress (Bjarkøy Strandberg et al., 2015; Sturt, Dennick, Due-Christensen, & McCarthy, 2015) and some studies also reporting high levels of depression (Barnard, Skinner, & Peveler, 2006; Moulton, Pickup, & Ismail, 2015). It

may be that some of these difficulties have their origins early in the experience of the disease, developing within the initial adaptive process following diagnosis. Indeed, some studies have identified that the type of support provided at diagnosis by family, friends, and health care providers (HCPs) has a long-lasting influence on adaptation to diabetes (Lawson, Bundy, & Harvey, 2007; Sharpe & Curran, 2006).

The majority of published studies and previous meta-syntheses exploring the experiences of living with T1D in adults have exclusively included people with longer disease duration who had either type 1 or type 2 diabetes. These analyses suggest that living with diabetes is an ongoing and multidimensional process with a focus on trying to balance life to the effects of the disease (Paterson, Thorne, Crawford, & Tarko, 1999) with key components of this process being: acquiring basic knowledge about diabetes (Beeney, Bakry, & Dunn, 1996; Campbell et al., 2003; Ingadottir & Halldorsdottir, 2008; Paterson, Thorne, & Dewis, 1998); developing the necessary self-management skills (Campbell et al., 2003; Hernandez, 1996; Ingadottir & Halldorsdottir, 2008; Paterson et al., 1998; Wilkinson, Whitehead, & Ritchie, 2014); establishing supportive relationships with health care professionals (Campbell et al., 2003; Gask, Macdonald, & Bower, 2011; Ingadottir & Halldorsdottir, 2008; Lawson, Lyne, Harvey, & Bundy, 2005; Paterson et al., 1998); recognising the seriousness of diabetes (Campbell et al., 2003; Ingadottir & Halldorsdottir, 2008); and fostering confidence in their ability to manage diabetes (Campbell et al., 2003; Hernandez, 1996; Paterson et al., 1999; Paterson et al., 1998; Ryan & Coates, 1998). While these insights are useful in elucidating and describing the experiences of a life with established diabetes, they are less useful in helping us understand the adaptive process during the formative diagnostic period which may have important impact on long-term outcomes for adults with T1D. Therefore, to support adults in preventing the development of complications and poor psychological well-being, we need a better understanding of the phenomena that influence the adaptation process in adults from the time

of diagnosis and into the early period of the disease. In this article, we present a meta-synthesis, the aims of which were: Firstly, to identify studies that explore the experiences of adults in relation to being diagnosed with T1D in adulthood and the initial adaptation to life with diabetes. Secondly, to synthesise the findings of these studies to identify conceptual underpinnings depicting the phenomena that shape and influence the early process of adaptation to life with T1D.

Methods

The aim of a meta-synthesis is to translate the primary qualitative studies in a related field into each other by combining the parts (the single study) to form a whole (the meta-synthesis) that produces more in-depth knowledge about the field than merely aggregating the findings of each study (Dixon-Woods et al., 2006; Noblit & Hare, 1988; Sandelowski, Docherty, & Emden, 1997). The synthesis explores commonalities and divergences in meanings and interpretations across the different studies to identify mutual key concepts that might not have been identified in the original studies (Britten et al., 2002; Noblit & Hare, 1988). While meta-syntheses of qualitative studies can be very powerful and informative, they are also technically challenging as there is often inherent heterogeneity between studies in terms of their theoretical underpinnings and methods of data collection and analysis (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). Therefore, it is important to use an open and rigorous approach to enable valid theoretical innovation. To this end we have used an adaptive framework for the analysis based on the methods of meta-synthesis outlined by Noblit and Hare (1988), and Dixon-Woods et al (2006). The synthesis addressed the following questions: What are the experiences of adults in relation to being diagnosed with T1D? What phenomena influence the early process of adaptation to life with diabetes? The meta-synthesis was undertaken in three steps as outlined below.

Step 1: Systematic Search and Selection of Studies

We searched MEDLINE, PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), BNI (British Nursing Index), ASSIA (Applied Social Sciences Index and Abstracts), Sociological Abstracts, IBBS (International Bibliography of the Social Sciences). MeSH, keywords and free text terminology as appropriate to each database were used to combine general terms defining adults with T1D (e.g. type 1 diabetes, T1DM) and terms relating to their experiences (e.g. perception, life world, identity) and adaptation (Shaw et al., 2004). We used validated methodological filters for identifying qualitative studies (Flemming & Briggs, 2007; McMaster University, 2014) and conducted citation and hand searches to extend study capture (the search result is summarized in supplement 1). We contacted experts in the field to identify additional studies and unpublished work.

We screened titles and abstracts for relevance according to all the following inclusion criteria; (1) qualitative study-design; (2) involving any participants with a diagnosis of T1D within five years; (3) participants were aged ≥ 18 years at the time of diagnosis; (4) containing directly identifiable verbatim quotes from these participants; (5) describing experiences of a T1D diagnosis; (6) exploring phenomena related to the early process of adapting to life with T1D.

We chose the limitation to five years diabetes duration to focus specifically on the early adaptive process and reduce the risk of recall bias relating to these initial experiences. We obtained full text for all potentially relevant articles selected based on the above criteria. We excluded articles if verbatim quotes could not be linked specifically to a person diagnosed with T1D within the past five years. The initial selection process was validated and agreed by a second researcher.

Step 2 Appraisal of Studies

The methodological quality of the included studies was appraised using the Critical Appraisal Skills Programme (CASP), which scores from 0-10 (Critical Appraisal Skills Programme, 2010). Excluding studies purely on the basis of methodological quality is not recommended as it can exclude potentially relevant content (Sandelowski et al., 1997). Therefore, we did not exclude studies if the source data were adequately reported to enable interpretation of meaning and hence contribute to the synthesis.

Step 3 Synthesising the Studies

We read the included studies carefully several times. We extracted data into a table with information on: context, research question, objectives; characteristics of the sample; design and methodology. In a separate table, we extracted first and second order constructs following the methods of Britten et al (2002) and Parsons et al (2014) (Britten et al., 2002; Parsons, Ismail, Amiel, & Forbes, 2014). The first order constructs represented the views and experiences of the participants (directly identifiable quotations) and the second order constructs represented the original authors' interpretations of these views and experiences in relation to the diagnosis and the adaptive process (expressed identified constructs). First order constructs were used to validate second order constructs. If key constructs were not supported by verbatim quotes attributable to adults diagnosed with T1D within the past five years the construct was excluded. In the absence of second order constructs these were developed independently from the first order constructs by two researchers then compared and validated by a third. We synthesised the combined findings in relation to people's experience of the diagnosis and the phenomena that underpinned their adaptive process and generated third order constructs within and across the studies by comparing and critiquing second order constructs against first order constructs. Commonalities and divergences across the studies were identified. We validated the third order

constructs by integrating them with the first order constructs from the original studies. The final step of the synthesis was to generate conceptual models of the phenomena that underpinned the early adaptive process by integrating the identified constructs expressed in a line of argument synthesis (Noblit & Hare, 1988).

Findings

The electronic database searches identified 1819 records and after removing 212 duplicates 1607 records remained. Five records were found through citations or experts in the field. Titles and abstracts were reviewed and 1536 records were excluded as they did not meet the inclusion criteria. Full-text versions of the remaining 76 records were obtained from which ten records relating to nine studies were included in the study (Audulv, 2013; Audulv, Asplund, & Norbergh, 2012; Doktorchik, 1991; Everett, 1999; Goldman & Maclean, 1998; Johansson, Ekebergh, & Dahlberg, 2009; O'Hara, Gough, Seymour-Smith, & Watts, 2013; Pender, 2010; Samson, 2006; Smith, 2010).

Overview of Included Studies

Studies originated from the UK (n=5), Canada (n=2) and Sweden (n=2). Two articles reported findings based on the same data material but analyzed with different focuses and both were included (Audulv, 2013; Audulv et al., 2012). While three studies exclusively included adults with new onset T1D (Everett, 1999; Johansson et al., 2009; Pender, 2010), five studies included participants with varied duration of T1D (Doktorchik, 1991; Goldman & Maclean, 1998; O'Hara et al., 2013; Samson, 2006), and one study included participants from a variety of chronic diseases (Audulv, 2013; Audulv et al., 2012). The studies were conducted between 1991 and 2013 and involved 124 participants of whom 17 women and 18 men had been

diagnosed with T1D within the previous five years. The age (where specified) ranged between 23 and 58 years. Diabetes duration ranged from four months to five years with two thirds having T1D for three years or less. Ethnic background was rarely stated. Table 1 provides details of the design and methods of the studies, the number and characteristics of adults diagnosed within five years participating in each study and in addition, the second order constructs reported.

The CASP scores varied from ten (Auduly et al., 2012; O'Hara et al., 2013; Smith, 2010) to three (Everett, 1999) with nine studies scoring six or above (Auduly, 2013; Doktorchik, 1991; Goldman & Maclean, 1998; Johansson et al., 2009; Pender, 2010; Samson, 2006). While the methodological quality of one study (Everett, 1999) was poor, it contained a large number of direct quotations from people with new onset T1D that could be utilized in the meta-synthesis.

< INSERT TABLE 1 ABOUT HERE >

Experiences of Adult Onset Type 1 Diabetes and the early Process of Adaptation

Five third order constructs were developed from the synthesis. These constructs identified the underlying phenomena that shaped and influenced the early adaptive process: disruption; constructing a personal view of diabetes; reconstructing a view of self; learning to live with diabetes; and behavioural adaptations. These constructs are presented below.

Disruption

This construct illustrated how adults experienced the diagnosis of T1D. The diagnosis was perceived as a major disruption to people's life trajectories and aspirations for the future. Adults with new onset T1D expressed their experience of the disruption in relation to the physical, psychological, and social aspects of their lives.

The initial experience of diabetes typically involved various physical symptoms. These symptoms were often insidious and confusing for the individual, leading to feelings of uncertainty as to what was happening to them (Johansson et al., 2009; Pender, 2010; Smith, 2010). Some people resisted acknowledging their symptoms and tried to minimize or explain away the symptoms (Pender, 2010, Johansson et al., 2009). Others experienced symptoms that were more severe and viewed the diagnosis as positive, at least initially, as the commencement of insulin reduced their symptoms (Everett, 1999; Johansson et al., 2009; Pender, 2010; Smith, 2010).

Receiving information on the diagnosis was generally perceived as shocking (Johansson et al., 2009; Pender, 2010; Smith, 2010). Psychologically the diagnosis required immediate adaptations in the person's outlook on their past, present and future possibilities and roles:

"I was the strong one in the family. And suddenly I'm this diabetic, and it's really hard to accept that you're not as healthy as you thought you were" (Goldman & Maclean, 1998, p. 744).

The diagnosis often provoked a feeling of being overpowered and people needed time to process the impact the diagnosis had on their lives (Doktorchik, 1991; Johansson et al., 2009; Pender, 2010). This emotional response was influenced by the manner in which the diagnosis was communicated and the type of support provided (Pender, 2010; Smith, 2010; Johansson et al., 2009). The psychological response to diagnosis was also reflected in the realization that diabetes does not go away but is a lifelong condition (Doktorchik, 1991; Everett, 1999; Goldman & Maclean, 1998; Johansson et al., 2009). This was expressed in feelings of loss and grief for the possibilities and flexibility of their previous life:

"After the initial diagnosis sinks in there is the pain of accepting the loss of your good health. Alongside this is the 'neverendingness' of it – that's when I think you need some emotional support" (Smith, 2010, p. 216).

Moreover, social disruptions in terms of relationships and in the context of work and life in general were also reported by some adults following their transition into diabetes (Johansson et al., 2009; O'Hara et al., 2013; Pender, 2010). They reported changes in their relationship structures, with family and friends becoming more concerned with the person's health and well-being rather than with their more regular conversations (Audulv, 2013; Goldman & Maclean, 1998). Another form of social disruption was the negative impact the disease had on their present employment and on future work opportunities (Pender, 2010; Smith, 2010).

Constructing a Personal View of Diabetes

This construct showed how adaptation to a life with diabetes was influenced by the person's perception of diabetes and its impact on their lives. An individual's perception of how serious the disease was and the impact it had on their health and life varied between individuals. Some people tended to minimize the significance of the disease in their everyday life: "It's not really that bad, it's just annoying the time it takes" (O'Hara et al., 2013, p. 1231). Others perceived the prospect of long term consequences of living with diabetes as more serious (Audulv, 2013; Audulv et al., 2012; Goldman & Maclean, 1998; Pender, 2010; Smith, 2010) with the potential to damage their bodies in the future: "If you want to feel well, you have to manage it so that it does not damage the body" (Johansson et al., 2009, p. 200).

Individual views of diabetes could be quite divergent in terms of whether participants associated or dissociated the disease with themselves. Some people seemed to develop a strong and sometimes overwhelming association between themselves and the disease (Everett, 1999; Goldman & Maclean, 1998; Johansson et al., 2009), viewing the diabetes as something that had taken over their sense of self. Such a response could lead to a preoccupation with diabetes and that it enforced restrictions on their lives: "I have to eat at set times. Diabetes dominates my routine" (Everett, 1999, p 151).

Other people dissociated their sense of self from their diabetes and viewed the diabetes as something that was outside of them to limit the impact the disease had on their lives (Everett, 1999; Johansson et al., 2009; O'Hara et al., 2013; Samson, 2006). In other circumstances, this disassociated orientation manifested as a more laissez faire approach to diabetes and self-management (Audulv, 2013; Audulv et al., 2012), leading to disengagement with practices such as attending to food and blood glucose monitoring:

“I feel like there are many other things going on ...in my life I just don't have the time energy or interest to monitor... it's sort of fifteenth on your list of priorities” (Goldman & Maclean, 1998, p. 745).

Reconstructing a view of self

This construct referred to how, for many adults in these studies, the diagnosis seemed to change their personal identity which in turn influenced the way they engaged with others and their future aspirations and goals. How they reconstructed their sense of self seemed to be related to past experiences and, as detailed in the previous construct, their view of diabetes.

Some people felt it was difficult and demanding to relate to the changes imposed by being diagnosed with a chronic condition and how this had an impact on their self-identity (Everett, 1999; Johansson et al., 2009; Pender, 2010; Smith, 2010). While some actively resisted the impact diabetes might have on their self-identity: “I can't be somebody else and I'm certainly not going to be somebody else because of this condition” (Smith, 2010, p. 262), others expressed a different view:

”Your whole opinion of yourself changes, everything changes. It's not just physically; mentally it really kind 'a throws you off...Like I'm not what I thought I was” (Goldman & Maclean, 1998, p. 744).

For some this could lead them to disengage with self-management to reduce the impact diabetes had on their identity (Doktorchik, 1991; Everett, 1999). For others, the consequences of having to redefine themselves as a person with diabetes could have a negative effect on their mood, causing feelings of anger and resentment (Everett, 1999; Goldman & Maclean, 1998; Johansson et al., 2009; Smith, 2010). They felt their personal behaviours were altered by diabetes which had a negative impact on their interactions in the social world possibly leading to social isolation. While for others the diabetes diagnosis did not have such a major impact on their sense of self or personal identity (Goldman & Maclean, 1998; Johansson et al., 2009). The type of response seemed to be related to the view they had constructed of diabetes.

An additional factor in reconstructing their self-view was how others responded to them as a person with diabetes (Goldman & Maclean, 1998; Pender, 2010). While the person's own sense of self may have altered they also found that others viewed them differently. This could lead to conflict as the person with diabetes wished to be treated as the same person as before and yet other people treated them differently (Audulv, 2013; Johansson et al., 2009; Smith, 2010). This could have a strong effect on people's view of themselves as a person with diabetes influencing their social adaptation with individuals adopting restrictive behavioural adaptations in response to the stigmatizing effect of diabetes. The stigmatisation was experienced in the way others felt at liberty to impose rules and judgements on them. For the person with diabetes such judgements tended to reduce their sense of personal autonomy (Audulv et al., 2012; Goldman & Maclean, 1998; Pender, 2010). Therefore, their relationships with significant others influenced their adaptive process. While for some these relationships supported adaptation (Doktorchik, 1991; Goldman & Maclean, 1998; Johansson et al., 2009), others experienced limited support or interactions that were perceived as antagonistic to the adaptive process (Everett, 1999; O'Hara et al., 2013; Smith, 2010). When family members attempted to show support by asking about their diabetes it could be perceived as unhelpful (Audulv et al.,

2012). In turn, the limitations imposed by diabetes could be challenging for family members and potentially affected their ability to provide support to the person with diabetes.

In adapting to life with diabetes some people struggled to find a balance between spending all their time on their diabetes to become the perfect person with diabetes and spending too little time on their self-management (Audulv et al., 2012; Everett, 1999; Johansson et al., 2009; Smith, 2010). This dilemma could influence their perception of their ability to engage with the demands of diabetes and could lead people to assess themselves negatively:

“I don't think I'll ever be under really excellent control. So I don't know if I'm ever going to feel good about myself, or if I'm just finally going to accept the way things are and not let it bother me” (Goldman & Maclean, 1998, p. 745).

This negative perception of self could lead to a judgemental attitude towards own behaviours. In addition, the person's underlying psychological adaptation and acceptance of the disease seemed to have an impact on their engagement with learning about the condition (Audulv, 2013; Doktorchik, 1991; Everett, 1999; Goldman & Maclean, 1998; Johansson et al., 2009; Samson, 2006).

Learning to Live with Diabetes

This construct reflected the learning that adults diagnosed with diabetes experienced as they made the multiple adaptations required to live with diabetes. The person's learning was multileveled and interacted with other constructs related to how they perceived diabetes and their reconstructed view of self. Learning could also be influenced by interactions with others including HCPs and services.

An important aspect of learning from the adults' view was the support they received from others, generally HCPs. People with T1D had different experiences of support. Initially people might find it daunting to learn about the potential impact diabetes may have on their life

situation. Preferences for the way supportive information was provided also varied, with some wanting choices over what they were told while others preferred clear guidelines. For some learning was supported and encouraged by HCPs which had a positive impact on how they adapted to diabetes.

Seeking additional information outside the healthcare system was a way to learn more about diabetes although such information was not always helpful (Everett, 1999; Pender, 2010). For some the information provided by HCPs was not sufficient for living with diabetes in the context of everyday life and they expressed a need to learn from other people with T1D who had personal experiences of the adaptive process (Pender, 2010; Smith, 2010).

Experiential learning was identified as a key learning strategy, trying out things was part of people's adaptation. Even if the experiment turned out not to work, it still enabled them to make further adaptations to their practices (Audulv, 2013; Audulv et al., 2012; Doktorchik, 1991; Everett, 1999; Goldman & Maclean, 1998; Johansson et al., 2009; O'Hara et al., 2013; Pender, 2010; Samson, 2006; Smith, 2010). Others reported using personal experiments to test the limitations of their disease. This process of self-experimentation seemed to be important in shaping how they adapted to and perceived diabetes, learning the parameters of the disease and how their behaviour can impact on it (Audulv, 2013; Audulv et al., 2012; Doktorchik, 1991; Everett, 1999; Pender, 2010; Samson, 2006).

Diabetes was perceived as a dynamic condition requiring constant change and adaptation. This was particularly true in the early stages of the disease and the constant adjustment required could feel overwhelming (Goldman & Maclean, 1998; Johansson et al., 2009; Pender, 2010; Samson, 2006). Understanding when to seek more information and knowledge regarding the changes that occurred in the early phases of the disease could be challenging (Goldman & Maclean, 1998; Johansson et al., 2009; Pender, 2010). If changes occurred ahead of the

person's understanding of the disease and without appropriate learning support, it might result in them reflecting negatively on their own ability to manage the disease.

Behavioural Adaptation

This construct elucidated how adults newly diagnosed with T1D needed to make a range of changes to their established behaviours, as well as adopting new behaviours. There were major differences in how people adapted their behaviours, suggesting an interaction with the previously identified psychological adaptations, their perception of diabetes, the way they reconstructed diabetes in relation to their self-identity and their approach to learning.

The diabetes diagnosis affected people socially and in particular their life structure and schedule, challenging the person to find a place for diabetes in their life. Pre-existing social structures and commitments could influence the way individuals perceived the impact diabetes had on their lives. While for some the structure of life and work was perceived as providing a positive context for adaptation to diabetes as they sought to bring diabetes into their routines (Auduly, 2013; Auduly et al., 2012; Johansson et al., 2009; Smith, 2010); for others, these structures, and work in particular, were privileged over the behavioural demands of managing their diabetes: "...because if you are working you have to wash your hands, it's filthy. It's working on the walls, it's freezing over there. On the job there's nowhere to wash your hands. It's all right now. Definitely not testing as much" (O'Hara et al., 2013, p. 1233).

People used a range of strategies to adapt their behaviours. Some individuals preferred more flexible strategies regarding their self-management behaviours, while others adopted more rigid methods. In the data, there were examples of how being flexible could be an adaptive strategy enabling the individual to choose from different behaviours in response to changing circumstances (Doktorchik, 1991; Goldman & Maclean, 1998; Samson, 2006). People who adopted more flexible strategies also seemed more orientated to use experiential learning in

adapting to diabetes. They also applied flexibility in terms of their level of attention to behaviours (Audulv, 2013; Goldman & Maclean, 1998). For example, they could choose to do blood glucose testing more or less intensively:

“At the moment I am experimenting with eating different foods, so I want to know how that is affecting me so I am testing four times a day” (Everett, 1999, p. 151).

There were other individuals who preferred more rigid strategies regarding management of their diabetes which could be reflected in their behavioural adaptations. While there was some sense of control and security for them in following this strategy, it could also impose restrictions on their lives (Audulv et al., 2012; Everett, 1999; Johansson et al., 2009; Smith, 2010). This less flexible model could also be challenging when the pattern of the day was disrupted or the context changed, such as during holidays. Again, this could be restrictive as the person may avoid situations or contexts where they could not apply their rigid model. Limited knowledge or following a fixed regimen prescribed by HCPs could be reasons for choosing this strategy.

Conceptual Models

As highlighted, the identified third order constructs seem to be interactive. When viewed collectively it is possible to consider how these underlying phenomena inform a more nuanced understanding of the complex ongoing processes of early adaptation in an adult diagnosed with T1D. In Figure 1 we propose a model to capture these potential interactions and express them as a process of adaptation within their social world. This process is likely driven by their underlying psychological orientation and thinking styles together with their interactions with others. In addition, the person must also address their diabetes within their life context, which may necessitate significant changes in personal relations and their social habitus.

<INSERT FIGURE 1 ABOUT HERE>

The model presented in Figure 1 suggests that the diagnosis initiates a disruption to habitual life. The person's response to the disruption requires that they need to construct a view of diabetes and reconcile this with their own self-identity. To do this they must develop strategies to enable them to live as a person with diabetes. This involves learning about themselves, the condition and their experiences in the social world. This learning is influenced by the support they receive and their experiences. These adaptive processes may have a significant impact on the person's behavioural adaptation. In turn, their experiences of adjusting habitual behaviours and learning new behaviours impact on their perception of diabetes and of themselves as a person with diabetes. It has been clear from the synthesis that there is variation within these adaptive processes. We illustrate this variation in Figure 2, which tries to capture some of the continua expressed within the different constructs within the process of adaptation. This model details the different styles of adaptation people identified. These styles may have both positive or negative impacts on the adaptive process and ultimately their self-management behaviours and whether they develop diabetes complications. The model could potentially be used as a discussion tool with patients.

<INSERT FIGURE 2 ABOUT HERE>

Discussion

The synthesis has provided new insights into the early process of adaptation that occurs following a diagnosis of T1D in adulthood. From the data, it is evident that the diagnosis has an immediate disrupting impact on physical, psychological, and social aspects of life. This finding is resonant with Bury's (1982) work, which described the emergence of chronic illness as a biographical disruption (Bury, 1982). In the original studies, the disruption was mainly described in the context of bodily changes or change in identity. Our work extends the interpretation of the original studies by suggesting interplay between the physical changes that occur to the body and the psychological and social stress it brings to bear on the individual.

This disruption demands a process of adaptation and can trigger psychological distress. This early adaptive phase may have longer-term consequences as beliefs and behaviours related to diabetes are formed. Hence, early supportive intervention should address the person's distress and help them develop the positive adaptive thinking styles and behaviours that would help prevent long-term complications and enhance their sense of well-being.

While the studies included in this meta-synthesis highlighted some specific features of the process of adapting to diabetes, our synthesis has added a deeper understanding of the process by identifying how these underlying phenomena interact within the early adaptive process. Furthermore, our synthesis has identified how the disrupting impact on physical, social and psychological aspects of life, instigates a wide range of adaptive strategies which shape how adults recently diagnosed with T1D contextualise diabetes within their present and future life constructions.

The synthesis shows that the early process of adaptation may be linked to how people construct a view of diabetes and how this view interrelated with self-identity are important aspects of adaptation. We have also observed that this early formation of diabetes and self-identity seems to shape adaptive strategies and behaviours later. The way an individual constructs diabetes was often expressed in terms of a conflict between their life in general and the demands of the disease. Our observations suggest that it takes root early in the disease's course and can affect self-management behaviours negatively and hence impact long-term outcomes. While previous studies have described various patterns and strategies of self-management (Pender, 2010; Audulv, 2013; Audulv et al., 2012) our synthesis has identified the diabetes dilemma, the conflict between the sense of self and the idealised view of how diabetes can be managed. The notion of being the 'perfect person with diabetes' and being able to live a normal life might seem irreconcilable for many adults in these studies, leading to a negative view of diabetes and lack of confidence in their ability to manage diabetes. While other studies have identified this

conflict in people with longer diabetes duration (Campbell et al., 2003; Ingadottir & Halldorsdottir, 2008; Karlsen & Bru, 2002; Ryan & Coates, 1998; Wilkinson et al., 2014), we see here that it takes route early in the disease trajectory potentially influencing learning and self-management behaviours negatively. Such perceptions may be unwittingly reinforced by HCPs by setting unrealistic goals for people with T1D a practice that may also negatively affect the relationship between the person with diabetes and the HCPs; (Maclean, 1991; Snow et al., 2014; Wilkinson et al., 2014; Zoffmann & Kirkevold, 2005). Therefore, providing adequate psychological support to people at the time of diagnosis to foster realistic perspectives on themselves and life with diabetes may reduce the often-identified negative self-perceptions, maladaptive behavioural responses and diabetes distress (Berry, Lockhart, Davies, Lindsay, & Dempster, 2015; Bjarkøy Strandberg et al., 2015; Karlsen & Bru, 2002; McKnight et al., 2015; Pallayova & Taheri, 2014).

In contrast to children, adults must adapt to diabetes in the context of a life already well established in the social world. Grief and mourning over the loss of their well-known lives was evident in the accounts of participants in the reviewed studies, although the impact of these feelings was not acknowledged in all studies. This sense of grief is not unique to diabetes; it has also been reported in relation to other chronic diseases (Charmaz, 1983; de Ridder et al., 2008; Frank, 2013). It has been observed that feelings of anger and resentment towards a chronic disease can affect the ways in which people come to terms with their loss and their adaptation to the disease (Ambrosio et al., 2015; Aujoulat, Luminet, & Deccache, 2007). The responses of the social world to them both in terms of their relationships, and in terms of employment and their economic well-being were also seen to be influential. Diabetes can be stigmatising with the person being constrained during interactions with others because of their diabetes, which can be frustrating for the individual and have a negative impact on their sense of self, their view of diabetes and ultimately their adaptive behaviours (Browne, Ventura,

Mosely, & Speight, 2014). Therefore, when supporting adults recently diagnosed with T1D, recognition of their lost life and the development of psychological and behavioural strategies to deal with and anticipate the social sequelae associated with diabetes could again encourage positive adaptation.

Accepting diabetes has been associated with the ability to balance the demands of diabetes with living a 'normal' life (Campbell et al., 2003; Hernandez, 1996; Paterson et al., 1998). Again, acceptance is not limited to diabetes but has been described as an influential aspect in many other chronic conditions (Ambrosio et al., 2015; Aujoulat et al., 2007). Indeed, accepting diabetes and finding this balance may be challenging for many (Lo & MacLean, 2001; Richardson, Adner, & Nordstrom, 2001). A key influencing factor may be the way an individual learns to deal with their diabetes. The synthesis shows that this learning can take many forms such as information seeking behaviours and experiential learning strategies. This learning begins from the moment of diagnosis and immediately requires actions such as injecting oneself with insulin and responding to bodily and visual feedback on self-management behaviours. Without some supportive guidance, this may lead to the development of unhelpful adaptive behaviours and thoughts (Karlsen & Bru, 2002; Maclean, 1991; Taylor, 1983; Wilkinson et al., 2014). In some cases, unsupported learning activities may lead to risk taking behaviours and fixed ideas that could become an impediment to future learning (Celano, Beale, Moore, Wexler, & Huffman, 2013; Colagiuri & Eigenmann, 2009). Again, this indicates the need for early intervention to introduce person-centred learning styles and appropriate information support while recognising the emotional and social impact diabetes has on the person's life. This is in keeping with studies on the early adaptive process in other chronic diseases (Dennison, Yardley, Devereux, & Moss-Morris, 2011; Kneck, Klang, & Fagerberg, 2012) which also emphasises the need for ongoing support as reflected in our synthesis. While

our synthesis focused only on adult onset T1D, the phenomena underpinning the early adaptive process may be transferable to other chronic diseases.

Finally, the theoretical models we have identified emphasise and illustrate the interactivity between the identified constructs. The models introduce a more dynamic expression of the findings within the collected studies. These models may help inform the development of early stage supportive interventions. The key message would seem to be that behavioural adaptation begins early and is shaped by emotional reactions to the disease, the person's view of diabetes and the impact this has on their sense of self and the influence of the social world. While clearly adaptation will be influenced by prior personality traits and thinking styles, there may be a window of opportunity to shape some of the adaptive processes through interventions in clinical practice that reflect the psychosocial phenomena of that process. In so doing, consideration should be given to: the emotional response to the diagnosis; the development of informed experiential learning and self-reflection; the promotion of personal and social coping strategies; and perhaps most importantly enhancing their self-worth. This may also require a degree of normalisation of their experiences such that they do not feel isolated.

Limitations

The trustworthiness of the findings of a meta-synthesis is restricted to the quality of the primary studies. In our meta-synthesis, we did not exclude any studies based on quality and while most were assessed as having adequate quality some were at a lower level. However, all studies contained enough primary data for us to be able to develop constructs even when the studies were of a poorer quality. Another inherent issue in meta-synthesis is the issue of methodological heterogeneity (Sandelowski et al., 1997), which was evident to some extent in this review although most studies followed similar analytical models. It has also been contended that this heterogeneity is beneficial as it extends the range of views analyzed (Pope,

Mays, & Popay, 2007). While there was some methodological heterogeneity, it was possible through a rigorous process within our team to take the extracted data to a higher interpretive level and develop a deeper understanding of the complexity within the early adaptive process. While the included studies span over two decades with potential significant differences in patient experiences due to advances in medical and technical treatment, we did not observe any differences according to time of publication.

It is striking that the participants were all from Western societies with easy access to health care which limits the transferability of the findings to less affluent countries and countries with less access to health care. A further potential concern in relation to our analysis was that some studies had participants with longer disease duration and one study had participants with other chronic conditions. However, we were able to bracket our analysis to adults diagnosed with T1D within the past five years by cross checking first order construct sources to validate our third order constructs.

Conclusion

The meta-synthesis has provided a deeper understanding of the phenomena that underpin the adaptive processes following a recent diagnosis of T1D in adulthood. The study identified that a diabetes diagnosis has an immediate disrupting impact on physical, psychological, and social aspects of life. This disruption requires the newly diagnosed individual to construct a personal view of diabetes as they need to reconstruct how they go about their everyday life. At the same time, a process of learning how to live with diabetes is initiated that in turn influences behavioural adaptation. The findings indicate that while there are differences between individuals, the early adaptive process may shape long-term behavioural patterns and psychosocial outcomes. Having expressed the interrelated phenomena associated with that process, the synthesis reveals some important areas for supportive intervention that may enhance the adaptive models adopted by adults when diagnosed with T1D.

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